

NPM #1: The percent of newborns who are screened and confirmed with conditions mandated by their State-sponsored newborn screening programs (e.g. phenylketonuria and hemoglobinopathies) and who receive appropriate follow up as defined by their State. (National Newborn Screening and Genetic Resource Center)

Impact on National Outcome Measures: The Wisconsin NBS Program is a core public health program that is a collaborative effort between DHFS and the State Lab of Hygiene. The NBS Program specified in Wis. State Statute 253.13 and Administrative Rule HFS 115, is a population-based service that mandates all infants born in Wisconsin be screened for congenital disorders.

a) Report of 2002 Major Activities

1. Newborn Screening—Population-Based Services—Infants

In 2002, 67,435 infants were screened. Cystic fibrosis screening now screens for 27 mutations increasing the detection of cystic fibrosis on newborn screen to 99%.

2. Diagnostic Services—Direct Health Care Services—CSHCN

The Department provides necessary diagnostic services, special dietary treatment as prescribed by a physician for a patient with a congenital disorder and follow-up counseling for the patient and his or her family.

3. Newborn Screening Advisory Group—Infrastructure Building Services—Infants

Formal recommendations were made to the Department to add five aminoacidopathies to the Wisconsin NBS panel of disorders. The Wisconsin NBS Advisory Group formalized physician action plans for timely response to positive newborn screening results of a life-threatening nature. Implementation of an internet package tracking system better tracks the transport of specimens to the state laboratory.

b) Current 2003 Activities

1. Newborn Screening—Population-Based Services—Infants

The Wisconsin NBS Program has begun screening for five additional disorders on the NBS Panel. Disorders include: Maple Syrup Urine disease, Homocystinuria, Tyrosinemia, Citrullinemia, and Argininosuccinic Acidemia. This increases the number of congenital disorders screened for in Wisconsin to 26.

2. Development of Educational Materials—Enabling Services—Pregnant women

Professional healthcare guides and consumer educational materials are being updated to reflect the expansion of the NBS panel. Parent information brochures will be available in English, Spanish, and Hmong. The NBS Education Subcommittee has been allocated one-time Title V MCH/CSHCN Program funding to promote the NBS program throughout Wisconsin. Fact sheets for disorders on the

NBS panel are in development. Educational displays are being created for placement in each of the five public health regions in Wisconsin.

3. Purchase of PKU Formula and Food Products—Direct Health Care Services—CSHCN

The NBS Program is currently evaluating policies related to the provision of dietary formulas and nutritional supplements to patients.

c) 2004 Plan/Application

1. Newborn Screening—Population-Based Services—Infants

All infants born in Wisconsin will be screened at birth for 26 congenital disorders.

2. Purchase of PKU Formula and Food Products—Direct Health Care Services—CSHCN

The Department will define nutrition services and formalize guidelines for providing nutritional supplements to children with congenital disorders identified by NBS.

3. Dissemination of Educational Materials—Enabling Services—Pregnant women

Newly developed educational materials and NBS displays will be disseminated to promote NBS throughout Wisconsin to both consumers and healthcare professionals.